Learning to Live Life in a Wheelchair With MS

by DEBRA ROBERT

Multiple Sclerosis Wheelchair: Just Roll With It

There have been times where MS weakness, dare I say, ‘floppiness,’ has dropped me square into my wheelchair. I have to chuckle about this because I don’t have just any wheelchair.

Mine is a slightly garish contraption decorated with its own Technicolor dream coat. It is bright lavender and blue and green. It has cheesy rhinestones lining the frame and a flashlight hanging on the armrest.

There is no hiding when in this chair. It is an attention-getter worthy of Better Midler’s Off-Broadway mermaid routine. Of course, there is a story as to how it came to be.

'When I First Had a Relapse That Rendered Me too Weak to Walk'

My husband Randy and I moved to the historic and artsy community of Lake Worth, Florida a few years back, around the time I was diagnosed with MS.

We live ten house lengths from downtown, which might best be described as the main street USA with a beachy, artistic flair. Lake Worth is also known for its tight-knit, yesteryear kind of feel where the shop owners know everyone, and one cannot go ten feet without a friendly hello or start a conversation.

When I first had a relapse that rendered me too weak to walk the single block that it takes to get downtown. After this happened, I resisted leaving our cottage at all.

I could not stomach the thought of having to be wheeled to my own stomping ground in a stupid chair. Feelings of resentment and spite churned inside of me. I felt as though I’d sooner become a hermit than be pushed around like a houseplant in a shopping cart, on display for all to see.

As fate would have it, Randy grew up knowing how hard it can be for a headstrong woman to give in to certain allowances when hit with a debilitating disease. His mother, God rest her beautiful soul, had MS for decades. Randy recognized this wheelchair avoidance of mine was a hurdle we needed to jump, and we needed to do it sooner, rather than later.

'My Husband Wheeled My Ugly Back and Chrome Chair Onto the Porch'

One evening, my not-so-subtle husband wheeled my ugly black and chrome chair onto the porch and insisted I get ready because “we are going out.'

I did not appreciate his tone, but I heeded his remark and begrudgingly plopped my spiteful self into my ugly, utilitarian, contraption of shame. I suppose one could say on that night, Randy literally pushed me out the door.

We both stayed silent as we slowly progressed up the street getting oriented with the new roles we both had to play. All the while, the bumps and uneven textures of the sidewalk vibrated my numbed muscles and rattled my bones.

I was stunned and put off by these new sensations. I had been up and down this stretch of sidewalk countless times. I never realized how much more one could get to know a stretch of concrete until I was subject to being rolled upon its surface.

I felt like screaming. I was not prepared for these unsettling sensations. None of this was mentioned in any section of the “What Is It Like to Have MS?” handbook. This whole situation felt wrong. It unnerved me and put me in a rather dark place.

I felt a second surge of information overload when we encroached the populated flurry of our little downtown. Everything seemed foreign from the vantage point of my seated position. I curled into myself, shying away from all the people and sounds and smells wafting from restaurants and bars.

'Inside I Knew I was Over-Reacting'

I had always felt full of life when I went downtown, strutting my stuff in my latest pair of colossal heels, and waving to everyone we knew. Where now, was the tall, confident chic I used to see looking back at me in storefront window reflections? I was not handling this experience as well as I thought I would.

Inside I knew I was over-reacting. This was a relapse, after all, not a life sentence, not yet anyway.

I reminded myself I’d soon be walking around again, albeit with a cane. I’d use it gladly. It was a small give for independence, in comparison to being anchored down to an ugly wheeled prison.

I thought of others who did not have the luxury of rebounding from a relapse. Still, the whole chair scenario felt ugly to me. I had an icky feeling inside that I knew came from a time, long ago.

Next page: What Debra's fears are and how her husband changed her views on wheelchairs.

'I Had Feared Only Two Things'

When I was around ten years old, I had feared only two things, a wheelchair and the old rusted oil burner on legs that loomed in my basement. I was terrified that both of these things were out to get me.

I had to build up the courage to race past the evil burner in order to get to our playroom. I was certain if I was not fast enough it would chase me down on its horrible rusted legs and try to eat me.

I had the same fear of the wheelchair that laid in wait at my friend Jane’s house.

Jane had a very old aunt who lived with her family. I never saw her aunt when I visited and no one in the house ever explained anything about her. All I knew was that there was always an odd smell and awful gagging sounds and strange vocalizations coming from her room.

Her door was never opened more than a crack and through this crack all I ever saw in the musty room was the ominous and creepy wheelchair facing the door, ready to attack.

Much like the oil burner in the playroom scenario, I dreaded having to use the bathroom at Jane’s house. I used to gather my nerve to run past the evil wheelchair in order to reach the bathroom safely. I’d quickly shut the door behind me, gasping for breath. I was afraid of what I did not understand.

I look back now and feel bad about the whole situation. I was a very young. Symbols and impressions, coupled

with my rather boisterous imagination were all I had to conjure up the sum of the situation.

I never knew what became of Jane's aunt, and it saddens me to realize that in times gone by, many people hid loved ones away as shamed secrets.

'He Erased Some Negative Stigmas [About Wheelchairs] With Two Acts of Love'

I never told Randy about these recollections. I did not have to. Unknowingly, he erased some negative stigmas from my psyche with two demonstrative acts of love.

1. **My wheelchair was nowhere to be found for a time.** Randy told me he had to work on it. When he brought it back home it had been transformed into a work of art, worthy of any gallery downtown. He decided if it was going to be part of our lives, it had darned well better be an extension of who we are. It fits me to a ‘T’ and is yet another act of defiance, along with my purple hair. If I am going to need a wheelchair, it may as well be a cool wheelchair.
2. **My attitude toward being pushed downtown has done a complete 360 both literally and figuratively.** I now start to smile in gleeful anticipation as we approach the downtown streets. When we get to the center of town and cross the intersection to hit our local pub, Randy takes a moment in the crosswalk, to spin me around in a complete grand and wide circle on par with musical theatre choreography. I used to cringe a bit, embarrassed at this rather bold maneuver. Now, it has become something of a crazy-happy ritual. This may be seen by some as an over-the-top call for attention. I do not care.

To me, it is a somewhat romantic and heartfelt gesture on the part of my husband and caregiver. This is his way of belaying the fears I have of what may become my permanent future.

Our tandem dance move in the street not only erases some of my fears that were planted in my consciousness decades ago, it tells me that I am not alone. I have someone who is with me and will make the best of a bad deal from the card deck of life.

I used to dread this Hollywood musical move in the center of town. Now I squeal with glee, spinning in my chair. I throw my arms up in the dance of it all. Onlookers who know us shout out, tourists and folks dining al fresco stop and stare. Puzzled looks, grins, and sometimes, tiny applause are all a part of this 15 seconds of life.

I know now, that the reactions we get are often built on the experiences people have had, or have not had, with a disability. I suppose in some way, I am doing my part to blast out the misconceptions and awkward feelings or fears some people have of disability aids.

I can no longer run away from wheelchairs. I’m okay with this. As for my fear of basement oil burners, I’m just glad I live in Florida.